

FASD: Knot Alone

Volume 2, Issue 1

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FASD Center Kicks Off New Community Subcontracts

“We need to stop the fragmentation of services.”

— Professional testifying at an FASD Center town hall meeting

Families, professionals, and people with FASD have learned the hard way that finding services for FASD can be like looking for a needle in a haystack. Actually, it's more like looking for 100 needles in 30 or 40 haystacks scattered across the State. That's why creating an infrastructure for FASD services is one of the major goals of the FASD Center. At a meeting in Albuquerque, New Mexico in November, the Center kicked off 20 projects designed to help meet that goal.

The new project subcontractors will work to incorporate FASD into existing service delivery systems. They will also help generate ideas for research and move the field forward. Ten projects focus on prevention, seven on treatment, and three on both prevention and treatment.

The award of the subcontracts resulted from a major effort by the FASD Center. The Center e-mailed a notice about the request for proposal to more than 2,000 interested parties and posted an announcement on its Web site. Sixty-three organizations submitted proposals.

The 20 subcontractors were selected through a rigorous review process involving more than 50 reviewers. Each proposal was reviewed by three reviewers, including FASD Center Steering Committee members, field trainers, consultants, and staff. The 20 organizations were selected based on the ability to complete the tasks successfully.

The projects span the country (see map). Eight projects address rural populations and six are in urban areas. Ten projects include children in their target audience. Four include American Indian/Alaska Native populations, one focuses on Hispanics, and one focuses on African-Americans. The projects span a range of services:

- Two projects address criminal justice and juvenile justice, with the goal of identifying people in these systems who have FASD.
- Two projects have systems of care for mental health and are working to integrate FASD prevention and treatment into the system.
- One project involves a health maintenance organization integrating alcohol screening into its mental health unit and maternity clinic.
- Several prevention projects focus on women at high risk or likely to be at risk of having children with FASD.



Subcontractors chat at the kickoff meeting

In This
Issue

New
Community
Subcontracts





- Two projects deal with residential services for youth with FASD, including screening, diagnosis, and intervention.
- One project will work with physicians on the type of screening that triggers a referral for diagnosis.

The subcontractors' tasks are to:

- Integrate FASD prevention or treatment activities into an existing service delivery system.
- Find ways to continue the project after funding ends.
- Measure outcomes.

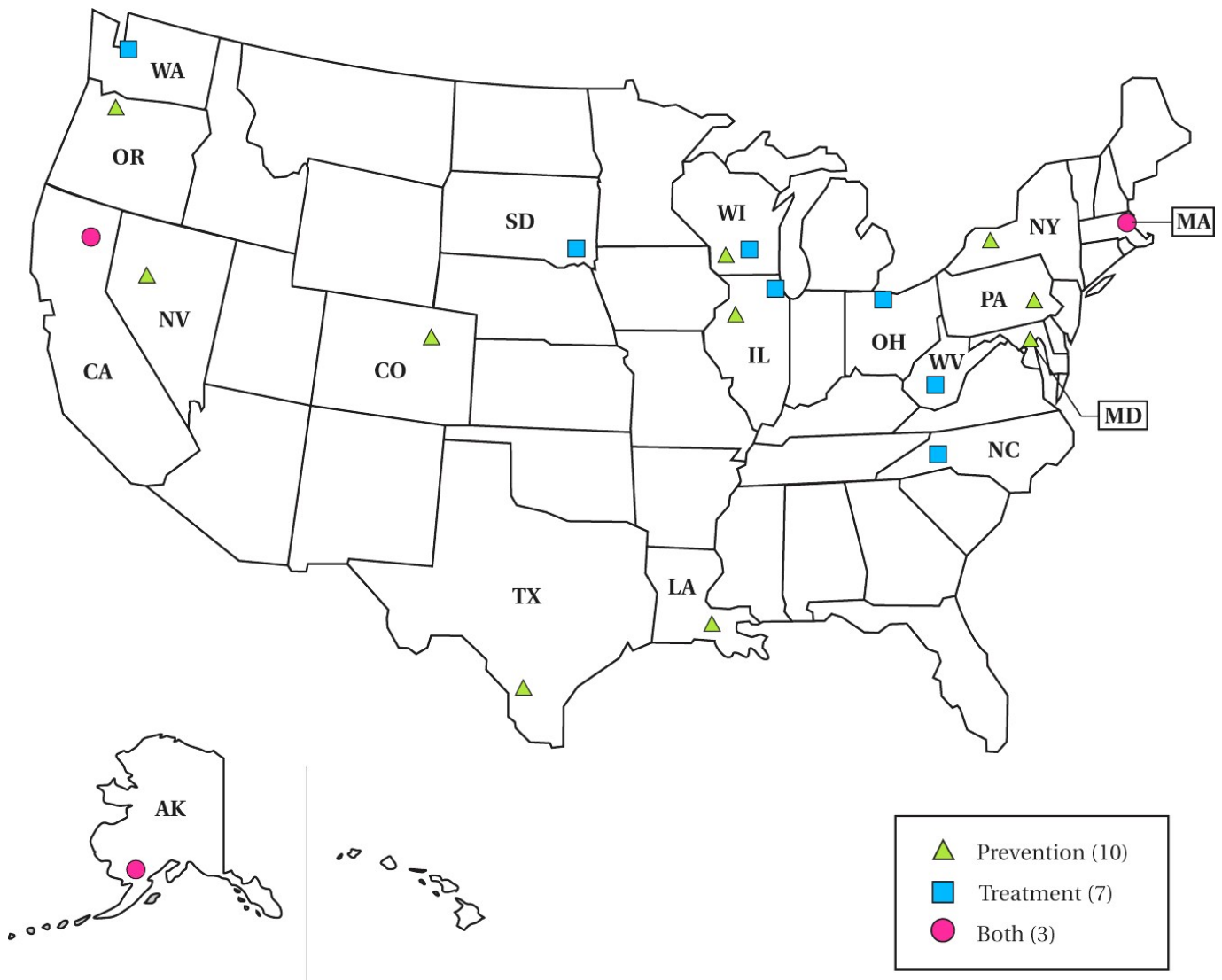
Year 1 of the 5-year subcontracts is a planning year. Subcontractors will organize a committee, perform a

needs assessment, and develop strategic, implementation, and evaluation plans. The FASD Center will oversee the projects and provide technical assistance, with help from its technical assistance partners, SPECTRA and Conwal.

At the kickoff meeting in Albuquerque, New Mexico, subcontractors learned about the FASD Center, their role in FASD prevention and treatment, and the project tasks. Now the projects are up and running. The FASD Center plans to make relevant project information available on the Web. The 20 subcontractors are listed in the box.



Subcontractors at a workshop at the kickoff meeting



Community Subcontractors

- ARC Community Services, Inc., Madison, WI
- Baltimore City Healthy Start, Inc., Baltimore, MD
- Bristol Bay Area Health Corporation, Dillingham, AK
- Bucks County Council on Alcoholism and Drug Dependence, Inc., Doylestown, PA
- Capital Area Human Services District, Baton Rouge, LA
- Children's Research Triangle, Chicago, IL
- Double ARC, Toledo, OH
- Institute for Health and Recovery, Cambridge, MA
- Lassen County Health and Social Services Department, Susanville, CA
- Mission Hospitals, Inc., Asheville, NC
- Native American Rehabilitation Association of the Northwest, Portland, OR
- New Frontier Treatment Center, Fallon, NV
- Peer Assistance Services, Inc., Denver, CO
- Serving Children and Adolescents in Need, Inc., Laredo, TX
- Sinnissippi Centers, Inc., Dixon, IL
- The Children's Home of Wheeling, Inc., Wheeling, WV
- Unity Health System Park Ridge Hospital, Rochester, NY
- University of South Dakota, Vermillion, SD
- University of Washington, Seattle, WA
- University of Wisconsin-Madison, Madison, WI



From the Field

Two of the FASD Center's key partners include the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and the Centers for Disease Control and Prevention (CDC). This issue of *FASD: Knot Alone* adds a column, "From the Field," that highlights their efforts. This inaugural feature provides background on NIAAA and CDC and their FASD efforts. Future issues will highlight in more detail some of the programs and scientific advances related to FASD. For more information about NIAAA, visit www.niaaa.nih.gov. For more information about CDC's FASD efforts, visit www.cdc.gov/ncbddd/fas/.

FASD Research at the National Institute on Alcohol Abuse and Alcoholism

Established in 1970, NIAAA is part of the National Institutes of Health (NIH), the agency responsible for medical and behavioral research. NIH provides leadership and direction to programs designed to improve the Nation's health, including research on the

causes, diagnosis, prevention, and treatment of mental, addictive, and physical disorders. For more information about NIH, visit www.nih.gov.

NIAAA focuses on the causes, consequences, treatment, and prevention of alcoholism and alcohol-related problems, including FASD. Research and training of scientists is supported through a program of extramural grants at leading U.S. research institutions, an interdisciplinary National Alcohol Research Centers grant program, and a program of intramural research. The wide range of program areas supported include:

- Alcohol and pregnancy
- Genetics
- Epidemiology
- Neuroscience and behavior
- Alcohol metabolism
- Alcohol-related medical disorders
- Medication development



- Health disparities
- Health services and alcohol policy research
 - Underage drinking

NIAAA also collaborates with other parts of NIH, other agencies of the U.S. Department of Health and Human Services (DHHS), and the international community.

ALCOHOL Research & Health



ALCOHOL-RELATED BIRTH DEFECTS
AND SYMPTOMS

NIAAA has supported basic, epidemiologic, and clinical research on FASD for more than 30 years and continues to be the leading funding agency in the United States for research on alcohol and pregnancy. NIAAA funded the first research grant to study the

effects of prenatal alcohol exposure on offspring just one year after the landmark scientific publications in 1973 by Kenneth Jones and his colleagues. Their work described fetal alcohol syndrome (FAS) in the United States for the first time.

Many important questions regarding the effects of alcohol on the fetus have been answered through NIAAA-supported research. For example, research has demonstrated that:

- Alcohol is a potent teratogen that can cause birth defects independent of other maternal factors.
- Alcohol dose, timing, and pattern of exposure determine the specific signs and symptoms of FASD.
- Brain damage associated with FASD is irreversible and causes lifelong problems.
- FASD occurs in about 1 percent of the U.S. general population.
- Alcohol causes brain damage in the fetus by interfering with cellular growth and maturation and causing brain cells to die prematurely.

Despite these advances, many challenging questions remain. Current research funded by NIAAA includes:

- Studies of mechanisms of alcohol-induced malformations
- Effects of alcohol on brain development and subsequent brain functioning
- Experimental therapies
- Genetic and environmental variation in susceptibility to detrimental effects of fetal alcohol exposure
- Identification of biomarkers of exposure

Laboratory studies have identified several cellular and molecular mechanisms that may contribute to FASD defects. These studies may help identify biomarkers for early diagnosis and may provide a basis for possible preventive in utero therapies or development of therapeutic agents for individuals with FASD.

Research also includes epidemiologic and clinical studies to determine factors, such as cultural norms, that place women at risk of having children with FASD. This research will help in developing and targeting prevention and intervention efforts. The development of methods to confirm alcohol use during pregnancy or fetal exposure to alcohol can help identify women at high risk and target high-risk infants for evaluation by medical specialists. NIAAA also supports research that develops or evaluates strategies at the community, health provider, and family levels to prevent drinking by pregnant women, especially those at high risk.

The effects of binge and low-level or moderate drinking on prenatal development are of special concern because these patterns of drinking are so prevalent among women of childbearing age around the world. Longitudinal human studies have shown that childhood behavior problems can occur when mothers consume 4 or 5 drinks on one occasion per week during pregnancy. Neuroimaging studies of children with FASD, in conjunction with neurobehavioral tests, are providing clues about the nature of neurodevelopmental deficits and may lead to better diagnosis and treatment of these disorders.



NIAAA also chairs the Interagency Coordinating Committee on Fetal Alcohol Syndrome (ICCFAS), created in 1996 in response to a report by an expert committee of the Institute of Medicine (IOM). The IOM report, *Fetal Alcohol Syndrome: Diagnosis, Epidemiology, Prevention, and Treatment*, recommended that NIAAA chair a Federal effort to coordinate FAS activities. IOM stated that the responsibility for addressing the many issues relevant to FASD transcended the mission and resources of any single agency or program. ICCFAS includes representatives from the Department of Education, Department of Justice, and seven DHHS agencies. Since 1996, individual agencies have made substantial progress in expanding or adapting existing FASD programs.

NIAAA recently launched the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), a cooperative research agreement to inform and develop effective interventions and treatment approaches. CIFASD comprises highly integrated, multidisciplinary research projects in five domains: basic science, neurobehavior, morphology/neuroanatomy, neuropharmacology, and early intervention. It is anticipated that CIFASD will create unprecedented opportunities for collaboration and integration of resources, both nationally and internationally, that will significantly increase the translation of important scientific discoveries to clinical practice.

Fetal Alcohol Syndrome Prevention Team at the Centers for Disease Control and Prevention

CDC has been involved in FAS-related activities since 1991. The Fetal Alcohol Syndrome Prevention Team at the National Center on Birth Defects and Developmental Disabilities focuses on preventing FASD, ameliorating these conditions, and supporting families and caregivers of individuals with FASD. CDC's work involves developing systems to monitor exposures and outcomes, conducting epidemiologic studies to identify maternal risk factors for giving birth to children with FASD, conducting public health research, and implementing prevention and intervention programs.

Since 2001, CDC's FASD programs have expanded from 8 cooperative agreements in 8 States to 38 cooperative agreements in 22 States and 2 international activities. This article focuses on CDC-sponsored studies and projects that have been completed or are nearing completion and how their findings and products can be used to enhance public health.

Project CHOICES, an intervention study targeting nonpregnant women at high risk for an alcohol-exposed pregnancy, has completed both a feasibility study and a randomized controlled trial. The goal was to test the efficacy of a motivational intervention aimed at decreasing risky drinking and improving contraceptive effectiveness among women of childbearing age. Virginia Commonwealth University, Nova Southeastern University, and the University of Texas at Houston participated. Results of the feasibility study and the contents of the successful intervention have been published and are available on CDC's Web site.

At Virginia Commonwealth University, a one-session adaptation of the intervention targeting college-age women, Project Balance, also has been completed. Final results are being prepared for publication. The U.S. Preventive Services Task Force has endorsed the use of such brief interventions as a "best practice" for reducing risk drinking in primary care settings.

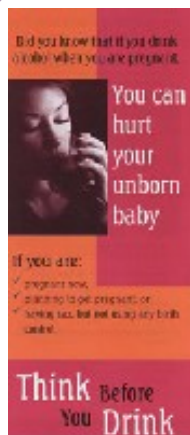
In 2003 and 2004, CDC initiated the State-based FAS Prevention Project in Colorado, Michigan, Minnesota, Missouri, North Dakota, South Dakota, Oregon, and Wisconsin. The purpose of the program is to:

- Develop, implement, and evaluate statewide and targeted programs for FAS prevention, including the identification of high-prevalence areas or selected groups of childbearing-aged women at high risk for an alcohol-exposed pregnancy.
- Establish or enhance prenatal prevention programs to serve women at high risk.
- Establish or use existing systems to monitor the impact of prevention programs. The projects will adapt Project CHOICES strategies in State-funded primary care settings.





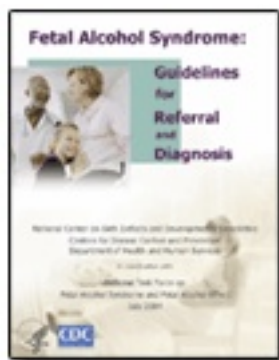
Four CDC cooperative agreements have developed and tested FAS educational curricula for parents and caregivers, school staff, and social service and law enforcement personnel. Grantees include the Arc of the United States, Education Development Center, National Indian Justice Center, and Double ARC. In addition, university-based projects at St. Louis University, University of



Iowa, and UCLA have developed, implemented, and evaluated targeted media campaigns to prevent alcohol-exposed pregnancies. The curricula and many of the media materials will be available from CDC in spring 2005. More information about these projects can be found on CDC's Web site at www.cdc.gov/ncbddd/fas.

Other initiatives include funding from Congress to develop diagnostic guidelines for FAS and other prenatal alcohol-related conditions and disseminate the information to medical and allied health students and practitioners. The new diagnostic guidelines, *Fetal Alcohol Syndrome: Guidelines for Referral and Diagnosis*, were released in July 2004

and are available from CDC's Web site. CDC also awarded cooperative agreements to Meharry Medical College and Morehouse School of Medicine, University of Medicine and Dentistry of New Jersey, UCLA, and St. Louis University School of Medicine to develop Regional Centers for the Education and Training of Medical and Allied Health Students and Professionals on Fetal Alcohol Syndrome and Other Prenatal Alcohol-Related Disorders. These programs provide speaker bureaus and training events for medical and allied health providers.



In 2003, CDC funded the National Organization on Fetal Alcohol Syndrome (NOFAS) to develop a K-12 FAS curriculum, an FAS clearinghouse and resource

center, an FAS public awareness campaign training guide, and culturally appropriate FAS prevention activities and products at the Cherokee Nation in Oklahoma. Products from the NOFAS project will be available in 2005.

CDC also has supported a five-site collaborative effort investigating effective intervention strategies for children with FAS and alcohol-related neurodevelopmental disorder (ARND). The Intervening With Children With FAS/ARND project will contribute to prevention science by providing a better understanding of services that should be provided. Collaborators in this project include the Marcus Institute of Atlanta, UCLA, University of Oklahoma, University of Washington, and the Children's Research Triangle in Chicago, Illinois.

Reports from CDC and NIH find that prenatal alcohol use among women in general and binge drinking among college students continue to pose health risks to women of childbearing age and their offspring. These reports signal the importance of continued FAS surveillance, prevention, and intervention.

Ohio Holds First State Town Hall Meeting on FASD

Ohio became the first State to organize its own town hall meeting on FASD on September 9, 2004. The Ohio FASD Initiative Steering Committee convened the meeting to raise awareness of FASD across the State and to identify effective interventions. The meeting was held on International FASD Awareness Day.

Service providers and families affected by FASD shared their experiences with Ohio First Lady Hope Taft, State officials, and policymakers. In all, 24 people testified. Their chief concerns included:

- Increased awareness campaigns regarding the risks of prenatal alcohol exposure
- Education about FASD across service systems
- Improved diagnosis and interventions
- Supportive services such as respite care

The testimony also called for the development of a continuum of accessible care for individuals with FASD,



including therapeutic foster care, residential treatment, educational support, medical care, legal assistance, and long-term housing options for adults.

In addition to focusing attention on FASD and gathering information, the town hall meeting also helped identify potential new members of the Ohio FASD Initiative Steering Committee. The committee was formed recently to spearhead the development of goals and objectives regarding FASD. It operates under the guidance of Ms. Taft in partnership with State agencies, parents of individuals with FASD, and a private organization called Double ARC.

The FASD Center for Excellence provided technical assistance to support the Ohio meeting. In 2002 and 2003, the Center convened 15 town hall meetings on FASD across the country. The Center encourages States and localities to organize their own town hall meetings to increase awareness and understanding of FASD, educate policymakers and service providers, and

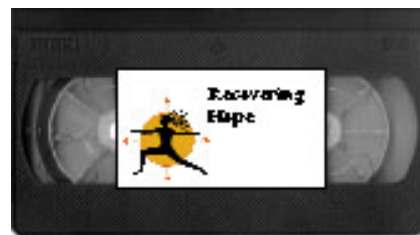
encourage changes in prevention and intervention practices.

Guidance for holding a town hall meeting on FASD is available on the Center's Web site at www.fascenter.samhsa.gov/gg/planningTownHallMeeting.cfm.

New Video Available: "Recovering Hope"

A new video from SAMHSA aims to bring education about FASD to a key audience: women in treatment for substance abuse. "Recovering Hope: Mothers Speak Out About Fetal Alcohol Spectrum Disorders" features eight birth mothers of children with FASD telling their stories—when they drank, why they stopped, how their children are affected, and what gives them hope. The video also features expert clinicians and researchers, who describe FASD and discuss diagnosis and treatment.

The hour-long video is divided into two half-hour segments to allow discussion time within treatment sessions. Two brochures accompany the video: one to prepare counselors or facilitators to screen the video and another for women to keep as a reference. The video also may be used by other audiences, such as support groups for women in recovery.



The FASD Center for Excellence developed the video package to help prevent and treat FASD. Research shows that both mothers of children with FASD and substance abuse treatment counselors lack basic information about FASD. For copies of "Recovering Hope," contact SAMHSA's National Clearinghouse for Alcohol and Drug Information at (800) 729-6686 and request item CR69, or visit ncadi.samhsa.gov.

New on the Web

If you haven't been to our Web site lately, check out what you've been missing:

- What You Need To Know: Independent Living for People With Fetal Alcohol Spectrum Disorders
- What You Need To Know: Understanding Fetal Alcohol Spectrum Disorders: Getting a Diagnosis
- Eight Magic Keys: Developing Successful Interventions for Students With FAS
- Convening "Hope for Women in Recovery" summits
- FASD-Related State Legislative Initiatives (PDF requires Adobe Acrobat Reader)



FASD Center Steering Committee Meets in New Mexico

The FASD Center for Excellence Steering Committee met on November 17 and 18 in Albuquerque. The participants bade farewell to several retiring committee members and thanked them for their service: Ellen Hutchins, Health Resources and Services Administration; Ken Jones, University of California, San Diego; Robin LaDue, University of Washington; John Richters, National Institute of Nursing Research; and Kathleen Sulik, Bowles Center for Alcohol Studies at the University of North Carolina. They also welcomed three new committee members:

- Rob Wybrecht, an expert on FAS who has been living with the syndrome for more than 30 years
- Jerome Romero, principal investigator for the New Mexico Statewide FAS Prevention Project and chair of the National Association of FASD State Coordinators
- Louise S. Ashkie, a program and project specialist for the FAS Project in Arizona and the FASD coordinator for the Navajo Nation



Rob Wybrecht



Louise S. Ashkie

Callie Gass, FASD Center Project Director, presented highlights of the annual report with details and data on Center activities in 2004, including providing training and technical assistance nationwide, expanding the Center Web site, and developing new publications and curricula. Several other speakers presented highlights:

- Diane Casto, manager for Prevention and Early Intervention Services in Alaska, discussed the successful second Building FASD State Systems meeting, held on May 5-6 in Kissimmee, Florida.

- Louise Ashkie reported on the Hope for Women in Recovery meeting and Birth Mother Network meeting, held June 29-30 in Phoenix.
- Rebecca Buchanan, FASD Center for Excellence for Materials Development Project Director; Julie Gelo, a parent and family advocate/trainer with the University of Washington; and Marceil Ten Eyck, a psychotherapist and counselor, screened "Recovering Hope," the video on which they had collaborated.
- Ted Buxton, task leader with the FASD Center, provided an overview of the Center's 20 new community subcontracts (see page 1).

The Steering Committee also reviewed recent external developments concerning FASD that affect the Center's work:

- Louise Floyd, CDC FAS Prevention Team Leader, provided an update on the new CDC guidelines for referral and diagnosis (see www.cdc.gov/ncbddd/fas).
- Philip May, a senior research scientist with the University of New Mexico, discussed findings from ongoing international research on the relative risks of FAS.
- Ms. Buchanan reviewed factors associated with alcohol use during pregnancy, including age, health status, and social supports, based on results from the latest National Survey on Drug Use and Health.
- Leah Oliver, Senior Policy Specialist with the National Conference of State Legislators, explained how State legislatures function and provided tips for educating policymakers about FASD.

The Steering Committee will continue to provide guidance to the Center and will reconvene in 2005.

Dear Dan



My stepbrother has been told he has alcoholism. His mother drank when she was pregnant with him. Is there a cause-and-effect relationship between them?

Sad Stepsister

Dear Sad:

Your interest in understanding the source of your stepbrother's problems is admirable. Regardless of the reasons for the alcoholism, having a supportive family will help him tremendously in dealing with his issues. Not every person prenatally exposed to alcohol will show negative effects, such as an increased risk of alcoholism. In addition, there are many unrelated reasons that an individual might develop alcoholism. For information about FASD, visit the SAMHSA FASD Center Web site at fascenter.samhsa.gov. It has some very good information that may increase your understanding of FASD.

Individuals with FASD are at higher risk for substance abuse problems. People use substances for many reasons. Individuals with FASD might have damage to specific areas of the brain that relate to the ability to process cause and effect. They may not associate destructive behavior with adverse effects. Some also have a tendency to follow others and may drink due to peer pressure. In addition, people sometimes use substances to block out emotional pain. Others try to self-medicate underlying disorders. An increased vulnerability to substance use may also be due to some genetic links in alcoholism that are currently being researched.

Your stepbrother does not necessarily have a fetal alcohol spectrum disorder because he has alcoholism. If he has other signs and symptoms that suggest a fetal alcohol spectrum disorder, I would strongly suggest encouraging him to seek a diagnosis. An accurate diagnosis is important. Some strategies for intervention and support will be more effective than others when working with an individual with an FASD.

The National Organization on Fetal Alcohol Syndrome maintains a Web-based directory at <http://www.nofas.org/resource/directory.aspx> where you may be able to find diagnostic services and other support organizations in your area. Your local chapter of The Arc may also have resources, or you can check The Arc's national Web site at www.thearc.org.

A good source for strategies in dealing with FASD is the FAS Community Resource Center (www.come-over.to/FASCRRC). Teresa Kellerman is the director of the FAS Community Resource Center and is an adoptive parent with over 20 years' experience in successful FASD intervention. In addition, the FASD Center has a database of resources on FASD, available at fascenter.samhsa.gov/resource/index.cfm.


Have a question for Dan?

E-mail fascenter@samhsa.gov and include "Dear Dan" in the subject line. Letters may be edited for content and space. Please indicate whether you want your name and State published.



Guest Editorial: FASD and the Flow of Oxygen

Joyce Jorgenson



May 3, 1973. There he was—a beautiful but tiny baby boy, just 6 weeks old, with big brown eyes and black curly hair wrapped in a pale yellow bunting. Who knew then what a diagnosis of fetal alcohol syndrome would mean for this innocent little life?

There I was, a young, naive mother filled with love and compassion for my precious new son. I had just promised the courts that I would be there to nurture, guide, and stand with him on this journey of life. Who knew then what that promise would mean?

There we were, both legally and emotionally bound together for life. I didn't know then what that promise meant. I didn't know then what fetal alcohol syndrome meant. I do now.

September 23, 1989. As it happens with so many families, I had been given a copy of *The Broken Cord* by Michael Dorris. Through an aching heart and a continuous stream of tears, I read the story of Adam, Michael, and their journey with FAS. For me, it was the very first time I had heard any other family member describe my reality. It was also the first time that I began to realize the complexity of FAS and the magnitude of my son's lifelong disability. And it was the first time that I knew that all the love and care in the world would not be able to cure him. The brain damage associated with FAS is lifelong and cannot be reversed. Yet, it was also the first time I knew that I was not alone. I had met my very first FASD soulmate within the pages of *The Broken Cord*.

May 6, 2004. I had just left the Orlando Airport after spending the previous 2 days at the Building FASD State Systems Conference in Kissimmee, Florida. The conference participants were just like me—mothers, fathers, brothers, sisters, and professionals looking for the best practices with respect to FASD. In the faces of so many passionate people gathered at the conference, I was reminded once again that I am not alone, much in the same way that I had been reminded so many

years earlier in the pages of *The Broken Cord*. I was at once encouraged and hopeful but sad and tired. After 30 years of living with FAS, I was encouraged to see so many individuals together addressing the difficult issues associated with FASD, but I was sad that we collectively are still such a small voice nationwide. Mostly I was tired.

As the plane crew prepared our journey toward home I drifted off into a light sleep. I awoke slightly to hear the voice of the flight attendant on the loudspeaker:

"In case of an emergency your masks will drop down. Place the mask over your face and tighten. Pull down on the cord and begin breathing as normal. Oxygen will begin to flow. If you are traveling with a small child or someone with significant needs, please secure your own mask first."

I thought about the many families that I knew who have loved ones with FASD. I thought about the dedication and passion we had as a group. I thought about the difficult stories and the painful examples we heard in testimony after testimony. I thought about my own experiences with my son and FAS and the ever-present risk he has of ending up in the correctional system as a result of sexually inappropriate behaviors. I thought about the many, many (way too many to count) team meetings when I raised the issue of the impact of FAS on his treatment and was met with blank stares. After all, FAS was not part of their clinical language. FAS does not fit into the Diagnostic and Statistical Manual as a diagnosis.

I remembered the tears of the grandmother as she told her family story and the questions from the family I had last met with as they searched for a meaningful support system for their 15-year-old son who already had been involved with the juvenile justice system. I remembered hearing the story of women trying to get both effective and gender-specific treatment in their States. So many stories, so many needs, and I am so tired.

I remembered the survey of States that I had recently read that suggested that 75 percent of respondents (division directors in mental health and developmental

disabilities departments) identified a shortage of qualified providers and 67 percent blamed inadequate information about clinical best practices as barriers to treatment. I remembered the medical director telling me that FASD is not an issue for mental health but rather an issue for the developmental disabilities system.

I thought about the President's New Freedom Commission report that suggested that it takes years for an emerging best practice to filter down from the Federal level to the State level to the community and clinical level. There is still so much that needs to be done to change the system. Most of the time, that change is led by families with our stories, our passion, our experiences.

I have spent a lifetime with my son under the umbrella of fetal alcohol syndrome. As I looked into the faces of the other families present at the meeting, I knew that my journey was not unique. I know that I am not alone. And I know that I am tired.

But I heard once again words of wisdom from the flight attendant and I share them now. Life is difficult (*in case of emergency*) for individuals with FASD and their families. Family support is a critical survival element, so find a support group. *Oxygen will begin to flow.* Self-care is often overlooked when you *are traveling with a small child or someone with significant needs.* Take good care of yourself. *Please secure your own mask first.* You are important and your own care must be valued. *Begin breathing as normal.* Read a book that has nothing to do with FASD. Take a bubble bath. Go out to dinner. Take time for yourself. And remember, you are not alone.

Joyce Jorgenson represents the State of New Hampshire at the Building FASD State Systems meetings. Among other things, she is the mother of an adult son with FAS. Ms. Jorgenson won the FASD Center's "Name the Newsletter" contest in winter 2004 with FASD: Knot Alone.

Editorial Guide

We welcome your thoughts on newsletter topics and other issues. E-mail fascenter@samhsa.gov and include "FASD Center newsletter" in the subject line. Or write to FASD Center Newsletter Editor, 2101 Gaither Road, Suite 600, Rockville, MD 20850. Include your name, city, and State. Unless otherwise requested, letters may be published with the author's name and location. Letters may be edited for space and content.

On the Road Again: FASD Center Training Update

What do you do when you've trained all over the United States and Canada? Go overseas, of course. The Center gave two presentations at FASAwareUK's first FASD conference in Wigan, England, in September. Approximately 150 service providers participated. Center staff also gave a presentation and question-and-answer session to psychiatric staff at St. Georges Hospital, Tooting, England, for 35 participants and a presentation to the psychiatric and mental health community at Springfield Hospital, London, England, for 20 people. Center staff and field trainers gave an additional 18 presentations to more than 600 people in 9 States, the District of Columbia, and Canada.

Topics included:

- "The Impact of FASD on Everyday Life: What Are the Struggles?"
- "The Impact of FASD on Everyday Life: How Can We Intervene?"
- "FASD: Why Is It Relevant to Me and What Do I Need to Know?"
- "Case Management for Individuals With FASD"
- "FASD and Co-Occurring Disorders"
- "Therapeutic Alliances: A Keystone for Building Positive Outcomes"
- FASD 101 and FASD 201
- Recent FASD efforts in the United States, including FASD Center activities



Want to know more? Contact our Information Resource Center at 866-STOP-FAS (786-7327), e-mail fascenter@samhsa.gov, or complete the Training/Technical Assistance Request Form on our Web site, fascenter.samhsa.gov.

Need Materials?

The National Clearinghouse for Alcohol and Drug Information stocks free fact sheets about FASD. Three

fact sheets in the “What You Need To Know” series are now available: SAMHSA Fetal Alcohol Spectrum Disorders Center for Excellence (RP01023), The Language of Fetal Alcohol Spectrum Disorders (RP01024), and Fetal Alcohol Spectrum Disorders: Tips for Elementary School Teachers (RP01025). Call 800-729-6686 to order.



Upcoming Events

National Conference—Fetal Alcohol Spectrum Disorder: Equality of Access: Rights and the Right Thing To Do

February 24-26, 2005

Victoria, British Columbia, Canada

For more information, contact UBC Interprofessional Continuing Education, 604-822-0054, e-mail ipconf@interchange.ubc.ca, or visit www.interprofessional.ubc.ca.

Fetal Alcohol Spectrum Disorders: Into Action
March 3-5, 2005

Portland, Oregon

For more information, contact Wendy Temko, 503-621-1271 or e-mail dmalbin@fascets.org.

10th National/3rd International Conference on Abuse of Children and Adults With Disabilities
March 14-16, 2005

Riverside, California

For more information, contact Del Cooper, 888-818-6298, ext. 224, e-mail delcooperarc@aol.com, or visit www.disability-abuse.com/cando/conf.

Circle of Sharing: Successful Journey

March 23-24, 2005

Winnipeg, Manitoba, Canada

For more information, contact Brenda Bennett, 204-770-4783, e-mail bennettb@mts.net, or visit www.aclmb.ca.

Motherisk Update 2005

April 20, 2005

Toronto, Ontario, Canada

For more information, contact the Motherisk Program, 416-813-8084, or visit www.motherisk.org.

If you're pregnant, don't drink.
If you drink, don't get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence